

Depression and Suicide Risk in MS: How Caregivers Can Help!

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“It is our hope that practitioners implement evidence-based practices to demonstrate that supportive services result in a healthier caregiver, an improved quality of care for the veteran, and a better quality of life for both the caregiver and the veteran.”

(Carol J. Sheets, LICSW, ACSW, VA National Director of Social Work, and Heather Mahoney-Gleason, LICSW, National Caregiver Support Program Manager, 2010)

Caregivers Can be at Risk, too...

- Depression/Anxiety
- Lower Quality of Life
- Self-esteem/Self-efficacy: How you feel about yourself!
- Other health problems:
 - Back pain
 - Fatigue
 - Insomnia
 - Shortness of breath

(Buhse, et al., 2015; Ghafari et al, 2014; Adelman, et al., 2014; Chen and Habermann, 2013; O'Connor and McCabe, 2011; Kahn, et al., 2007; Schultz and Beach, 1999)

Caregivers and Quality of Life

CG has a poorer Quality of Life if...

- A spouse
- Longer duration of caregiving
- Loved one has moderate or worse MS symptoms
- Unstable MS disease course



(Buhse, et al., 2015; Ghafari et al, 2014; Adelman, et al., 2014; Chen and Habermann, 2013; O'Connor and McCabe, 2011; Kahn, et al., 2007; Schultz and Beach, 1999)

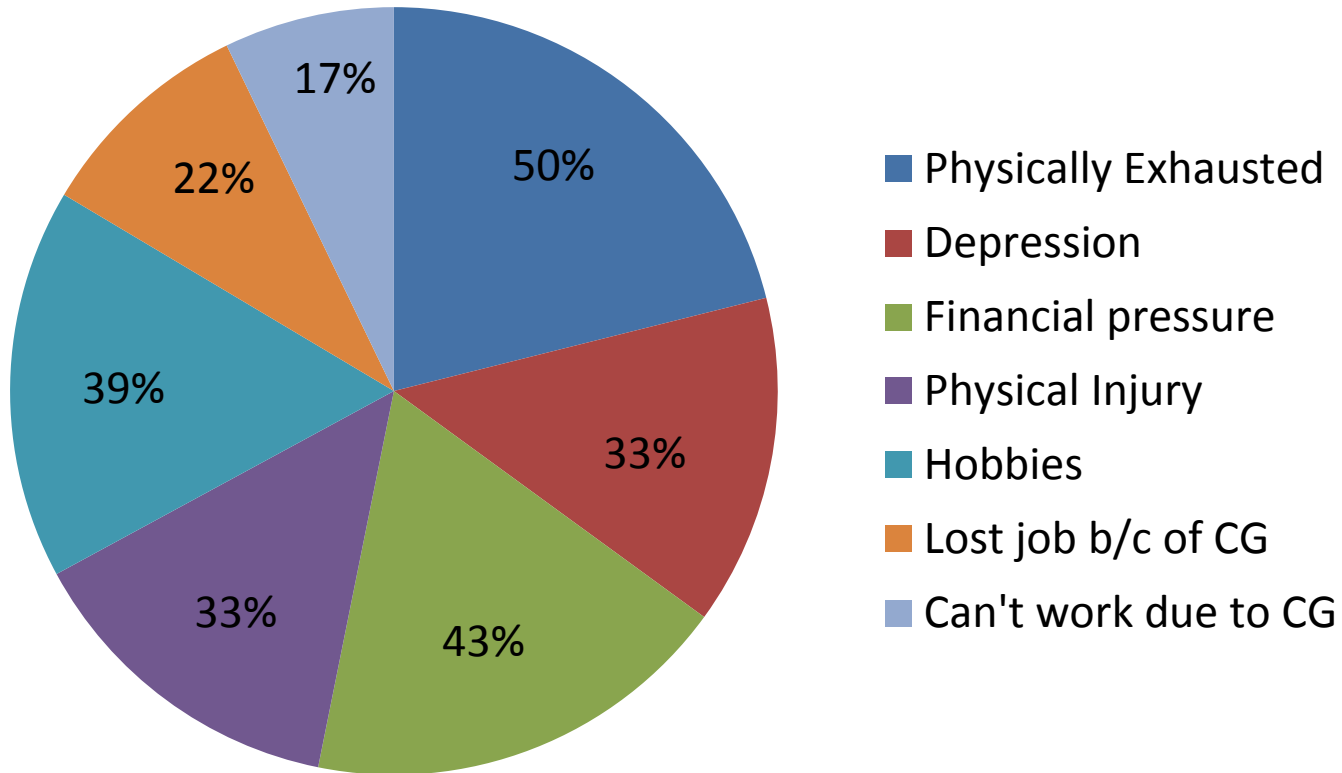
MS Symptoms That Can Increase Caregiver Burden

- Difficulty walking, balance
- Ataxia
- Fatigue
- Pain
- Incontinence
- Cognitive Impairments
- Depression/anxiety
- Bladder dysfunction
- Instability of symptoms
- Advanced MS symptoms



(Kumpfel, et al., 2007; Dunn, 2011; Bowen, et al., 2011; MS Caregivers Report, 2012; Chen and Habermann, 2013)

MS Caregiver Burden



(MS Caregivers Report, 2012)

We Encourage Caregivers to get support...

National VA Caregiver Support Line:



Most common reasons for calling

- Benefits
- In-home support services
- General Caregiver support/education
- Navigating the VA
- Questions about the Program of Comprehensive Assistance for Family Caregivers.

(Malcolm, 2015; Wright, Malcolm, Hicken & Rupper, 2015)

Understanding Depression in MS can Help...

Caregivers, friends, and family who understand Depression in MS can better help their loved one with MS.

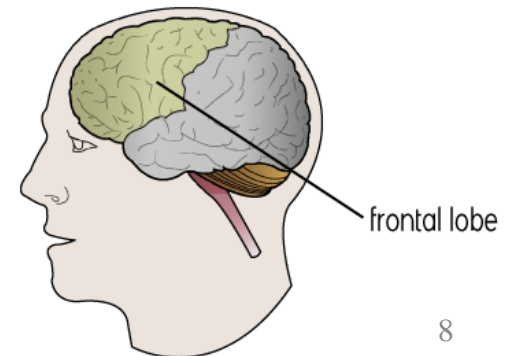
Adults with MS

- 1 in 4 chance of developing depression in their lifetime.
- 40-60% have reported depression symptoms
- 15.7% have DSM-V definition of depression (major depression, etc.)

Why?

- Depression & fatigue in MS is due to complex interactions in immune system and neuroendocrine system, and...
- Damage to areas in the frontal lobe in brain.

(Feinstein, et al., 2002, 2004, 2011)



Depression is more common in MS when...

- Earlier in the disease process... as people come to terms with MS diagnosis.
- When there is More Disability or trouble with Ambulation
- When there is Less Self-Care activities (physical activity, etc.)
- During periods of MS relapse.

(Systematic Review of literature in Current Neurology and Neuroscience Reports, Turner, et al., in press, 2016)

Veterans with MS and their Caregivers

- MSCOE study
- 451 Veterans with MS receiving care at VA
- Less depression if Veteran perceived they had...
 - Greater social support
 - Positive social interaction
 - Greater emotional/information support
 - Expressed affection

(Bambara, et al., 2010)

Fatigue and Depression – Double Whammy!

- Fatigue: 90% in people with MS
- Fatigue and depression can be hard to tell apart
- Significantly reduce patients' quality of life
- Reduce participation in daily activities.
- Less likely to do self care and positive activities (exercise, social activities, medication adherence) while depressed or fatigued.
 - More likely to use alcohol/substance abuse
 - More likely to stop MS disease modifying medications.

(Systematic Review of literature in Current Neurology and Neuroscience Reports, Turner, et al., in press, 2016)

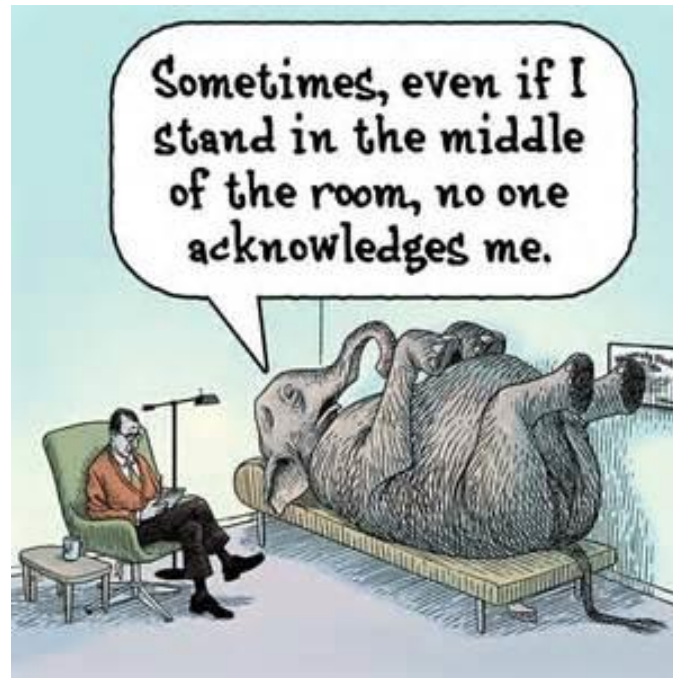
Self-Care: What Helps?

- Both of you! Increase Self Care activities, Social Support & Activities
- Get involved with groups: Caregiver groups, MS and Veteran Service Organizations
- Maintain Personal Relationships with Friends and Family, Social Life
- Talk to your loved one with MS about their depression & fatigue: How does depression show up for them? (sadness, loneliness, boredom, feeling suicidal)
- Discuss Treatment Options with your Medical Provider/Mental Health Provider
- Physical activity: Increase it!
- Motto: 5 -10 minutes of activity is better than nothing.
- Outside sunlight: at least 10 minutes a day of natural Vitamin D

Increase Self-Care Activities...

- What do you like to do to make yourself feel better or more safe?
 - Ex: Walking, listening to music, exercise, watching sunsets, gardening, meditation, yoga, reading, writing in journal

The Elephant in the Room...Suicide



Let's look at the whole picture

U.S. Suicide Statistics

- 10th leading cause of death in U.S.
- Cultural, regional & demographic differences
- Over 1 million attempts annually
- General population: 13.5% have thoughts of suicide (suicidal ideation); 4.6% attempt suicide

(from presentation at Consortium of MS Centers, Christine Moutier, MD, American Foundation for Suicide Prevention)

http://cmscscholar.org/wp-content/uploads/2016/05/cg_mood_suicide_moutier.pdf

There are Different Models Experts Use to Understand Suicide

Interacting Risk and Protective Factors

- Biological factors
- Psychological factors
- Social & Environmental factors
- Current Life Events

(from presentation at Consortium of MS Centers, Christine Moutier, MD, American Foundation for Suicide Prevention)

http://cmscscholar.org/wp-content/uploads/2016/05/cg_mood_suicide_moutier.pdf

Models to Understand Suicide:

Stress Diathesis Model

Suicide is the result of an interaction between environmental stressors and a trait-like diathesis (susceptibility to suicidal behavior) independent of psychiatric disorders.

Diathesis/Threshold Variables

- Predisposition to illness & stress needed for it to happen
- Mental illness
- Aggressions/impulsivity
- Poor adaptability/problem-solving
- Family history of suicide or mental disorder
- Childhood abuse
- Early loss
- Head injury
- Genetics
- Low serotonergic functioning: Low levels of serotonin
- **Chronic illness**
- Chronic substance abuse
- **Chronic pain**
- **Cognitive factors (decision making)**

Stress/Triggers

- Acute psychiatric episode (e.g., Depression, psychosis)
- Acute medical illness
- Stressful life event
- Acute substance use
- Psychological pain
- Panic attacks

VA Suicide Study 2016

- America is in a public health crisis - rate of suicide on the rise
- Recent study: 20 Veterans died from suicide each day.
- 66% from firearm injuries.
- 65% are 50 years or older.
- Risk Compared to U.S. civilian adults:
 - 21% higher among Veterans
 - 18% higher among male Veterans.
 - 2.4 times higher among female Veterans

(VA Suicide Prevention Program: *Facts about Veteran Suicide, July 2016*)

MS Centers of Excellence Study

- 445 Veterans with MS
- Mailed surveys linked with VHA computerized medical records
- Patient Health Questionnaire (PHQ): suicide item
- 29.4% suicidal ideation (~ 5% higher than Feinstein study of civilian outpatients)
- 7.9% persistent suicidal ideation over the last 2 weeks
- Suicidal ideation was associated with...
 - Younger age
 - Earlier disease course
 - Progressive disease subtype
 - Lower income
 - Not being married
 - Lower social support
 - Not driving
 - Higher levels of physical disability (mobility, bowel, bladder)
 - Depression

(Turner, et al., 2006)

People with MS and Suicide Risk

- People with MS are at **higher risk** for Suicide:
- Twice as much at risk than general population.
- Predictors:
 - Depression, Anxiety, other mental health difficulties
 - Being Younger
 - Male
 - Early in diagnosis (first few years)
 - Later as disability cumulates.
- Recommend that providers specifically screen for suicidality while screening for depression.

(Systematic Review of literature in Current Neurology and Neuroscience Reports, Turner, et al., in press, 2016)

Specific Studies: Suicide Risk – MS

Outpatient MS Clinic

- 28.6% endorsed lifetime suicidal ideation
- Living alone
- Family history of mental illness
- Social stress
- Major depression
- Anxiety disorder
- Alcohol abuse

(Feinstein, 2002)

Restricting Access Helps

- Restricting access to lethal means saves lives.
- Lock up or remove guns, stockpiled pills, knives, etc.

(Gunnell, 2003, 2007; Kreitman, 1976; Hawton 2002)

Caregivers Can Help:

Suicide Prevention Checklist

- ☐ **Power of 1:** One simple act has the power to make a difference to your loved one going through a difficult time...Reach Out!
- ☐ **Make a connection:** Let your loved one know “You’re not alone. “ Ask “Are You OK?”
- ☐ **Talk to your loved one:** about feelings/thoughts of suicide: **Don’t be afraid to ask** clearly and directly: **“Are you having thoughts about suicide?”**
- ☐ **Listen:** to their story, feelings, thoughts without judgment.
- ☐ **Reasons to Live “Turning Point to Life” & Choices:** Talk with them about what’s important to them and reasons to live. Talk about choices that can happen now.
- ☐ **Talk about Safety-for-Now Solutions:** Develop a safety for now plan. What can I do to help you stay safe? (lock up firearm, take pills away, etc.)
- ☐ **Safety Plan:** <http://www.suicidepreventionlifeline.org/Learn/Safety>
- ☐ **Safety Plan download** and list outside resources who can help you:
www.sprc.org/sites/default/files/Brown_St StanleySafetyPlanTemplate.pdf
- ☐ **Call Crisis Line together:** [1-800-273-TALK](tel:1-800-273-TALK) (8255) **press 1 for Veterans**
- ☐ **Call VA:** MS Care Team, Mental Health Provider, Primary Care Provider
- ☐ **Ask for Other Support:** from other friends/family/neighbors/support system
- ☐ **In Emergency: Call 911**

How To Talk to Your Loved One Who Is Talking About Suicide

- Be direct. Talk openly and matter-of-factly about suicide.
- Be willing to listen. Allow expressions of feelings. Accept the feelings.
- Be non-judgmental. Don't debate whether suicide is right or wrong, or whether feelings are good or bad. Don't lecture on the value of life.
- Get involved. Become available. Show interest and support.
- Don't dare him or her to do it.
- Don't act shocked. This will put distance between you.
- Don't be sworn to secrecy. Seek support.
- Offer hope that alternatives are available but do not offer glib reassurance.
- Take action. Remove means, such as guns or stockpiled pills.
- Get help from persons or agencies specializing in crisis intervention and suicide prevention.
- Call **[1-800-273-TALK](tel:1800273TALK)** (8255) press 1 for Veterans

(from www.suicidepreventionlifeline.org/gethelp/someone.aspx)

Sloan Caregiver Call, 2016

Be Aware of Feelings

- Many people at some time in their lives think about suicide.
- Most decide to live because they eventually come to realize that the crisis is temporary and death is permanent.
- On the other hand, people having a crisis sometimes perceive their dilemma as inescapable and feel an utter loss of control.
- These are some of the feelings and thoughts they experience:
 - Can't stop the pain
 - Can't think clearly
 - Can't make decisions
 - Can't see any way out
 - Can't sleep, eat or work
 - Can't get out of depression
 - Can't make the sadness go away
 - Can't see a future without pain
 - Can't see themselves as worthwhile
 - Can't get someone's attention
 - Can't seem to get control

(from <http://www.suicidepreventionlifeline.org/gethelp/someone.aspx>)

Know the Warning Signs

Depression, anxiety, low self-esteem, hopelessness, such as:

- Appearing sad or depressed most of the time
- Clinical depression: deep sadness, loss of interest, trouble sleeping and eating—that doesn't go away or continues to get worse
- Feeling anxious, agitated, or unable to sleep
- Neglecting personal welfare, deteriorating physical appearance
- Withdrawing from friends, family, and society, or sleeping all the time
- Losing interest in hobbies, work, school, or other things one used to care about
- Frequent and dramatic mood changes
- Expressing feelings of excessive guilt or shame
- Feelings of failure or decreased performance
- Feeling that life is not worth living, having no sense of purpose in life
- Talk about feeling trapped—like there is no way out of a situation
- Having feelings of desperation, and saying that there's no solution to their problems

Know the Warning Signs

- **If your loved one's behavior is dramatically different from their normal behavior, or...**
- **Appears to be actively contemplating**
- **Preparing for a suicidal act through behaviors, such as:**
 - Performing poorly at work or school
 - Acting recklessly or engaging in risky activities—seemingly without thinking
 - Showing violent behavior such as punching holes in walls, getting into fights or self-destructive violence; feeling rage or uncontrolled anger or seeking revenge
 - Looking as though one has a “death wish,” tempting fate by taking risks that could lead to death, such as driving fast or running red lights
 - Giving away prized possessions
 - Putting affairs in order, tying up loose ends, and/or making out a will
 - Seeking access to firearms, pills, or other means of harming oneself

Social Media and Suicide Prevention

- Facebook, Twitter, MySpace, YouTube, Tumblr, etc.
- Friend posts about...
 - wanting to die or to kill oneself.
 - feeling hopeless or having no reason to live.
 - feeling trapped or in unbearable pain.
 - being a burden to others.
 - seeking revenge.
- Encourage Friend to call the crisis line.
- Facebook has a suicide prevention safety feature on “Report Post”

www.suicidepreventionlifeline.org/media/12919/FB-One-Pager-for-AAS-3-.pdf

VA Aggressively Undertaking New Measures to Prevent Suicide

- Each VA has a Suicide Prevention Coordinator
- ***Veterans Crisis Line Expansion –***
- **1-800-273-TALK (8255) and then “Press 1”**
- Enhanced provision of care to women Veterans
- Expanding TeleMental Health Services

Crisis Lines

- National Suicide Prevention Lifeline:
www.suicidepreventionlifeline.org
1-800-273-TALK (8255)
- Veterans Crisis Line:
www.veteranscrisisline.net
- **1-800-273-TALK (8255) press 1**



Peer to Peer Suicide Prevention & Intervention Training

Community/peer interactive training in suicide first-aid skills

- Applied Suicide Intervention Skills Training (ASIST)
- Other workshops: SAFE TALK, Suicide to Hope
 - Created by evidence – based research at www.livingworks.net
 - Washington State: National Guard offers ASIST workshops to Veterans and their families once a month for free

National Guard & Reserve Members, Family, Friends

<http://usmilitarymatters.org> Free online training & resources

Other VA Resources for Caregivers

Coaching Into Care: 1-888-823-7458

www.va.gov/coachingintocare

- Assists family members and friends to help a Veteran seek care.

Free Self-Care Apps

- PTSD Coach: www.ptsd.va.gov
- CBT-i Coach for Insomnia: <http://t2health.dcoe.mil/apps/CBT-i>
- ACT Coach for depression: <http://t2health.dcoe.mil/apps/ACTCoach>
- Mindfulness Coach
www.ptsd.va.gov/public/materials/apps/mobileapp_mindfulness_coach.asp
- Moving Forward (problem solving skills)
<https://mobile.va.gov/app/moving-forward>

Suicide Prevention Resources

- VA Make the Connection: Connection to resources and Veterans stories: <https://maketheconnection.net>
- VA Suicide Prevention Program Factsheet: www.va.gov/opa/publications/factsheets/Suicide_Prevention_FactSheet_New_VA_Stats_070616_1400.pdf
- Veterans Crisis Line: www.veteranscrisisline.net
- The Power of 1: www.veteranscrisisline.net/ThePowerof1.aspx
- American Foundation for Suicide Prevention: www.afsp.org
- Suicide Prevention Lifeline: www.suicidepreventionlifeline.org
- American Association of Suicidology: www.suicidology.org

Resources

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Caregiver Resources

VA MS Centers of Excellence (MSCoE) Website: www.va.gov/MS

- ❖ MS Caregiver page: www.va.gov/MS/veterans/caregivers

VHA Resources

- ❖ VA Caregiver support line: (855) 260-3274 www.caregiver.va.gov
 - Online Caregiver Workshop: <https://va.buildingbettercaregivers.org>
 - Caregiver Workbook: [www.caregiver.va.gov/pdfs/Caregiver Workbook V3 Module 1.pdf](http://www.caregiver.va.gov/pdfs/Caregiver_Workbook_V3_Module_1.pdf)
- ❖ VA Respite Care: www.va.gov/GERIATRICS/Guide/LongTermCare/Respite_Care.asp

Paralyzed Veterans of America (PVA) Caregiver Support

www.pva.org/site/c.ajlRK9NJLcJ2E/b.6306123/k.B389/Caregivers_Support.htm

MS Organizations:

- ❖ National MS Society: www.nationalmssociety.org
Family and Relationships:
www.nationalmssociety.org/Living-Well-With-MS/Family-and-Relationships
Family Matters: www.nationalmssociety.org/Resources-Support/Family-Matters
- ❖ Multiple Sclerosis International Foundation: www.msif.org
Caregiving and MS: MS *in focus* magazine, Issue 9, www.msif.org/living-with-ms/ms-in-focus-magazine
Family Life: www.msif.org/living-with-ms/family-life
- ❖ MS Association of America: www.mymsaa.org
Care Partner Resources <http://mymsaa.org/journey/the-seasoned-traveler>